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ABSTRACT

This study tested the effects of two group-oriented supportive and educational approaches on the parents of children with cystic fibrosis (CF). Thirteen families were randomly assigned either to a group which received information on medical and technical aspects of CF or to a group which received instruction in communication skills in addition to medical and technical information. Didactic and experiential techniques were used to present communication skills. Measures of family interaction, child adjustment, locus of control, and understanding of CF were collected from parents and children prior to the intervention, immediately after the 4-session series and 6 months after completion. (Instruments used are included in the appendices.) Analysis of results indicated no differences between groups from the first to the final data collection times; communication training did not improve family functioning. However, parents reported greater satisfaction with didactic than with experiential techniques. The authors speculate that families in "chronic crisis" may find disease-related educational material more relevant and reassuring than process-oriented instruction and caution that clinical interventions with such populations need to be systematically evaluated because techniques designed for psychiatric populations may not translate directly to families coping with chronic medical problems. (Author/DB)

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Facilitating Positive Psychosocial Adaptation in Children with Cystic Fibrosis by Increasing Family Communication and Problem-Solving Skills

by

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A Research Report
to the
Cystic Fibrosis Foundation

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I. Introduction

Cystic Fibrosis, one of the more common childhood chronic diseases, has several features that accentuate its effects on child personality development. In addition to the physical effects of chronic, debilitating lung and gastrointestinal disease, the intense involvement of the family in treatment and the uncertainty of its prognosis contribute to a significant emotional burden on both child and family (Burton, 1973, 1974a, 1975; Patterson, 1973). These psychosocial phenomena have been the subject of much discussion and many observations, but only limited empirical research. In addition, the literature has little to offer in terms of descriptions of specific intervention programs that have been employed, and even fewer empirical evaluations of such interventions. The project upon which the present report is based was designed as a first step toward remedying this situation. By developing, documenting, and administering a replicable intervention program designed to help families better adapt to the stress of cystic fibrosis, we hoped to initiate research into such activities. More importantly, by dividing the study into several components that could be systematically evaluated for their effectiveness, the project sought to provide data which would allow workers in this field to provide services with increasing precision and sophistication, as well as adding to our theoretical understanding of how individuals and families cope with the stress of cystic fibrosis.

The specific focus taken by this project, suggested both by the existing body of literature and by our clinical experience, was to assess the relative usefulness of strictly cognitive, information-

focused group experiences as compared to a group experience which attempted to teach and facilitate basic family communication skills.

II. Review of Literature

1. Psychological impact of cystic fibrosis

Despite almost twenty years of accumulated literature, questions still remain as to the adequacy with which children and families cope with the stress of cystic fibrosis. Data in this area range from findings such as that by Lawler (1966), who found major psychological problems in all of his eleven subjects, to the findings of Rodgers (1974) who found that the majority of the children she studied had no demonstrable psychosocial problems, and that of Gayton, Friedman, Tavormina, and Tucker (1977), who found that on several objective personality instruments, "the overwhelming majority of children with cystic fibrosis do not present themselves as emotionally disturbed." More typical of the findings with regard to children, however, are reports of relatively significant levels of psychological disturbance in many of the children studied (McCollum and Gibson, 1970; Lawler, Nakielny, and Wright, 1976; Tropauer, Franz, and Dilgard, 1970; Burton, 1975). These disturbances tended to involve higher than usual levels of anxiety, insecurity, feelings of inadequacy, and especially in adolescent, preoccupation with death and disability.

It was clear to these authors from the beginning, that the most important unit of analysis in studying the impact of cystic fibrosis is the family. One of the first authors to write in this area, Juanita

Turk (1964), reported that the demands that the treatment and stresses of the disease placed on families presented significant problems for parents. A major problem identified in her paper was communication between family members. She noted that often families could discuss the treatment of the sick child, but nothing else. She found that 60% of her families never discussed the diagnosis with the child, and that communication was hampered among all family members, between parents, between parents and the sick child, and between the parents and siblings. Tropauer, et al. (1970), while reporting that only a small percentage of the mothers in their study were clinically depressed, noted a strong relationship between openness of communication and ability of the family to cope with the stress of the disease. They found that families who had difficulty sharing experiences and handling anxiety by open and supportive communication often were caught in a vicious cycle of further enstrangements and increasing difficulty in coping with everyday demands. In those families "where openness and mutual support prevailed, the child's illness had little disruptive impact on the family unit" (Tropauer, et al.). Similar themes are echoed by other authors (Boyle, diSant' Agnese, Sack, Millican and Kulczykuki, 1976; Gayton, et al. 1977; McCollum and Gibson, 1970). Interestingly, studies concerning themselves directly with siblings of chronically ill children (Gayton, et al. 1977; Lavigne and Ryan, 1979) have given an optimistic picture of the functioning of children in the family. Lavigne and Ryan, who studied diseases other than cystic fibrosis, reported that siblings of chronically ill children were at a

higher risk of developing adjustment or behavioral problems, but noted a complex pattern of relationships between the nature of the illness, the family functioning, and the adjustment level of the children in the family. They note that "information is needed on changes occuring within the family, between family members, and with peers that affects the siblings" (Lavigne and Ryan, 1979, page 626).

In summary, there appears to be a significant amount of evidence highlighting the importance of family functioning in general and family communication patterns in particular in determining the success of family and child adjustment to cystic fibrosis.

2. The parent group as an intervention technique

Given the indications for the importance of family functioning and communication in cystic fibrosis, it was surprising to find little material on clinical or experimental experience with attempts to improve such functioning directly. Davies and Addington (1973) reported that their early efforts to involve parents in group sessions met with little success, presumably, they felt, because of a high level of parental anxiety. More optimistically, McCollum and Gibson (1970) found that voluntary, informal group discussions made available to parents on a monthly basis were helpful in reducing the feelings of isolation experienced by individual parents. However, they comment on the tendency of these groups to maintain limits on the depth to which the anxieties of any one member of the group can be explored. One group (Goldberg, Kutscher, Lorin and Denning, 1973) reported on a survey of 57 Cystic Fibrosis centers in which they found that

over half of the centers sponsored some kind of formal or informal group meeting on a regular basis for their families. However, details about these groups were not reported.

Because the literature on the use of groups with families of cystic fibrosis patients was so sparse, that pertaining to the applicability of groups for other health problems and for normal families was also examined. This literature clearly indicated that such groups are a useful means of conveying a variety of information to parents, in addition to having an important supportive function (Mesibov and Johnson, 1981; Arnold, 1978; Hoffman and Futterman, 1971; Johnson, M.P., Ref. note 1). Such groups take a number of approaches, ranging from the teaching of behavior modification skills to socially oriented support. There is evidence that the group approach is particularly useful in teaching family communication skills to "normal" families (Gordon, 1970). Specific communication skills, of the kind that have been found so important by such pioneers in family therapy as Satir (1964) can be taught to groups of parents using this model, and at the same time the group setting allows experiential learning to take place.

Groups specifically designed to help parents deal with health problems in their children vary in their emphasis on such dimensions as peer support, cognitive teaching, communication skills, and dynamically formulated attempts to increase ego strength and decrease anxiety and guilt (Kornfield and Siegal, 1970; Ross, 1979; Kartha and Ertel, 1976; Saunders, 1977; Johnson, M.P., Ref. note 1). However, systematic evaluation of the effectiveness and importance of each of these com-

ponents or of the groups as a whole is lacking.

III. The North Carolina Memorial Hospital Experience

The evolution of parent education and support groups at the North Carolina Memorial Hospital (NCMH) Cystic Fibrosis Clinic actually began with an effort to establish, on a state-wide basis, groups for the increasingly large population of older adolescents and young adults with cystic fibrosis. Because of our clinical observation that many of these young people were relatively isolated and expressed considerable difficulty in discussing their disease and its concommitent limitations, several attempts were made to invite them to group meetings held concurrently with state-wide Cystic Fibrosis Chapter meetings. Several such meetings were held, and those who attended expressed considerable satisfaction with them, but the numbers of participants were disappointingly small. However, this initial core group did attempt to involve larger numbers of the state's young adult CF population in further group activities, sending invitations to approximately 65 young people. When only 8 responded, the effort was suspended for the time being, and the professionals who were involved in assisting the young adults attempted to determine why there were so many difficulties in having these young people come together. The impression was that several factors interfered with the success of such a group. One of these was that the young people expressed great difficulty in engaging in such a seemingly simple activity as leaving their home to attend the meetings in a neighboring city. Others admitted to a profound unwillingness to talk about their

condition openly, since that was something they had never done before. It became apparent that young adult groups, no matter how important this effort, may not have been the correct place to start. Family patterns seem to have been set far too early to have been influenced at the level of the age group that was being worked with. The pattern of blocked communication and dependency that we were observing had clearly begun many years earlier. Therefore, the importance was emphasized to the group of beginning with parents and younger children to attempt to provide needed information, reduce levels of anxiety, reduce isolation, and encourage normalization at an early stage.

With this in mind, a questionnaire exploring parental perceptions of need in this area was administered to all patients in the clinic; the response rate was about 80%. Parents were asked which aspects of cystic fibrosis they needed information about, where they felt more counseling was indicated, and how they preferred to have such counseling organized. Interestingly, parents generally denied having "problems" in the various areas polled, which included such diverse subjects as physical therapy, child development and behavior, and nutrition; however, they did indicate that they very much wanted more information.

In response to this questionnaire, four groups were set up. They were organized by age of child and included a group for families who had only one pre-school child, a group for parents of a pre-schooler with cystic fibrosis who also had other children, a group for the parents of school-aged children, and a group of parents of adolescents.

Clinics were organized in such a way that the groups could meet in conjunction with regular medical appointments; each group met approximately four times a year. The first group began with a film depicting a patient's daily life, "John" (W G B H, Boston, 1980) and continued with a discussion of future groups. Later groups involved a brief presentation, generally about 15 minutes, and then about 45 minutes of discussion. Topics included normal child development, physical therapy, nutrition, and the disease process. The actual amount of information conveyed was necessarily limited because of the brief didactic session, and focus was on parental discussion. After about a year and a half - encompassing approximately 5 meetings for each group - another questionnaire was administered exploring the families' reaction to the groups. Very positive feedback was obtained, although it was found that families expressed a preference for meeting with parents of children of different ages, rather than meeting in age-segregated groups. The staff ascribed the relative success of these groups, in contrast to the difficulties experienced in some clinics, to several factors. One was the involvement of clinic team personnel who were known to the parents and seen as supportive figures prior to the formation of the groups. Another was the emphasis on providing information about the situation of the families in general, and avoiding a focus on any one specific child. A third factor was the need to provide information that would be useful to families from a wide range of educational and intellectual backgrounds, from those who had not completed high school to those with graduate degrees. All of these issues were dealt with to some extent,

but certainly not resolved. As a result of this experience, it was felt that the supportive-educational parent group was indeed a useful intervention modality, but one that required more study and refinement.

IV. The Present Study

A. Goals

In addition to the literature cited and one experience with the first set of groups, a number of other clinical experiences suggested there was a need for more extensive information about the illness and its treatment, and for addressing directly the questions of family interaction and communication which the CF literature had suggested was so important. For example, we noticed that even children who had adjusted fairly well at earlier developmental stages sometimes developed significant adjustment problems as they approached adolescence. Upon further exploration, it sometimes developed that the parents had long-held firm beliefs, based on information received when the child was an infant, that, for example, the child would "never grow up." Since these beliefs were never discussed, either within the family or with us, the difficulties that tended to emerge when the child indeed did appear to be growing up could not be dealt with. School attendance could not be enforced, independence could not be granted, and so on. While clinical intervention with the individual families often resulted in significant improvement, it appeared that a preventative approach would be far more helpful in the long run. Similarly, families often had great difficulty in setting appropriate limits and expectations for their pre-schoolers,

and appeared to have few skills for discussing strategies among themselves or for communicating with the child, not only about CF in particular but about everyday life situations.

These experiences, combined with our review of the literature dealing with cystic fibrosis and with child rearing and development, led us to design the project reported here. The goal of the project was to investigate the relative effectiveness of two forms of intervention on several parameters, including knowledge about cystic fibrosis, family communication patterns, locus of control, and child adaptation. These two interventions were a Cognitive group format, which would instruct families in the medical aspects of cystic fibrosis in some detail, and a Cognitive-Communication group, which would, in addition to the medical information offered to the first group, provide instruction in specific techniques of parent-child and family communication designed to facilitate creative problem solving and to initiate open sharing of feelings.

B. Design

1. Sample

Participants in the project were 13 families, all of whom who had a child enrolled in the North Carolina Memorial Hospital Cystic Fibrosis Center. Of the 13 families who began the study, 11 completed the post-treatment evaluation and questionnaires. There were 5 families in which both parents participated in the groups; 7 families in which mothers only participated, and 1 family in which the father only participated. Of the families in which the mother only participated, 5 were two-parent families in which the father was unwilling or unable to participate.

Of the other 2, 1 was a single parent family headed by the mother, and the other began as a two-parent family with a non-participating father, and split up during the course of the study. These latter two families were, interestingly, the 2 that failed to complete the study. Omitting these 2 families, 16 adults completed most or all of the project activities. The families encompassed the full range of socioeconomic level, from families in subsistence-level farming to management level business and professional families. The children in these families ranged in age from infancy to 14 years of age. Table 1 provides details of the composition of each family.

2. Procedure

Participants in the project were recruited from the patients in the Cystic Fibrosis Clinic at North Carolina Memorial Hospital. All families were eligible, as long as the child being seen in the clinic was under 16 years of age. Approximately 35 families were mailed a letter briefly describing the project and asking the parents to respond regarding their willingness to participate in the program. Fifteen families responded to the questionnaire, out of which all but one wished to attend the meetings. All other families were contacted by telephone. Several of the families who had initially responded to the questionnaire were unable to attend because of work obligations or transportation difficulties, and several more families were recruited by telephone, resulting in a final pool of 13 families. In most cases, the reason given for non-participation was either distance to be traveled or job obligations. In fact, many of the families who were unable to attend would have had

Table 1

Sample Composition

Cognitive-Communication Group

Family Number	Parents Participating	Age of Child with CF	Age of Siblings	[1]CF Severity Rating	Parental Occupation
[2]1	Mother	3	--	3	trade
2	Mother	6	--	1	trade
3	Both	5	14	3	profession
4	Both	1	5	0	business
5	Mother	5	--	2	trade
6	Mother	1	4	0	trade
7	Father	14	--	1	technical
Cognitive Group					
8	Both	3	10,13	1	farm
9	Both	11	8,14	3	technical
10	Both	2	5	0	farm/ business
11	Mother	4	--	0	professional
12	Mother	12	--	0	technical
[3]13	Mother	4	--	1	clerical

[1]Severity rating derived as follows: 1 point each for height below normal curve, weight below normal curve, hospitalization in past 12 months. Thus range is from 0, least severe, to 3, most severe.

[2]Dropped out after two sessions; left state due to family dissolution.

[3]Dropped out after one session; new job and family crises.

to drive 4 or more hours each way, although several families from that distance actually did participate. While parents were informed initially that they would be compensated for their time and travel expenses, the difficulties of making the lengthy journey clearly posed a barrier.

After the participant pool had been established, families were assigned at random to either the Cognitive group or the Cognitive-Communication group. They were then informed by letter of the time, place, and date of the four group meetings, which were held on Saturdays at approximately monthly intervals in the fall of 1980. Families with children ages 4 year old and older were specifically asked to bring the child, and other families were given the option of bringing their children and taking advantage of child care services which were provided.

During the first meeting of the groups, the morning was devoted to collecting pre-test data from the parents and children. A luncheon was then served, followed by the first group meeting. Two hours was alloted for each meeting, although the leaders were given some leeway in the time that they utilized. The second and third group meetings were held on subsequent Saturday mornings. During the fourth meeting, the groups were held in the morning, and post-test data was collected in the afternoon.

Follow up data was collected during regular clinic visits, approximately 5 to 6 months after the last group meeting.

A summary of the procedures followed can be found in Table 2, and copies of the letters informing the families about the groups are given in Appendix A.

Table 2

Data Collected

Parents

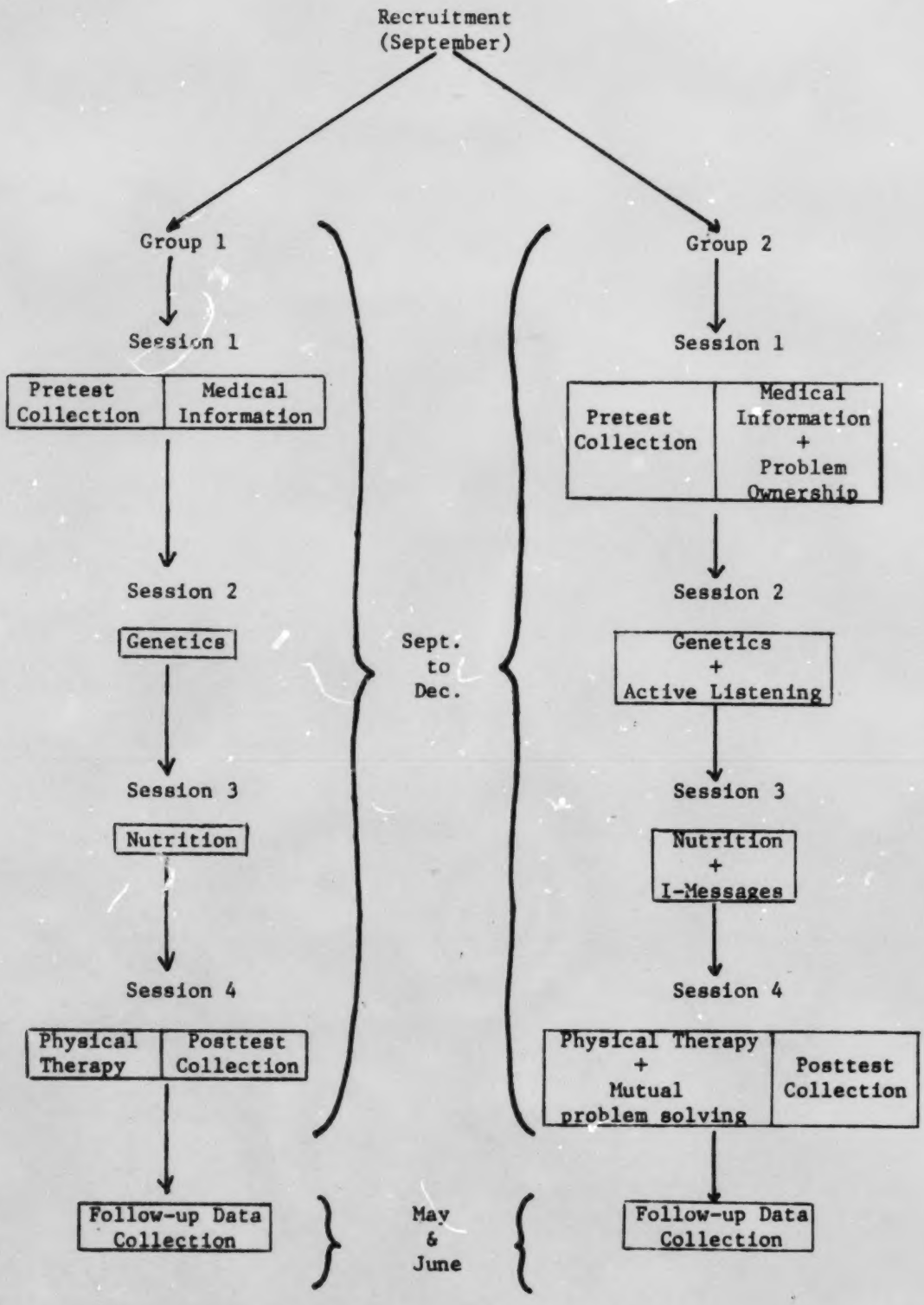
Pretest	Post-test	Follow-up
CF Knowledge Questionnaire	CF Knowledge Questionnaire	CF Knowledge Questionnaire
Moos Family Environment Scales	Moos Family Environment Scales	Moos Family Environment Scales
Multifactorial Health Locus of Control Scale	Multifactorial Health Locus of Control Scale	Multifactorial Health Locus of Control Scale
Nowicki-Strickland Locus of Control Scale	Nowicki-Strickland Locus of Control Scale	Nowicki-Strickland Locus of Control Scale
Child Personality Scale	Child Personality Scale	Child Personality Scale
	Evaluation of Groups	Child Health Locus of Control Scale

Children

Pretest	Post-test	Follow-up
CF Knowledge Questionnaire	CF Knowledge Questionnaire	CF Knowledge Questionnaire
Multifactorial Health Locus of Control Scale	Multifactorial Health Locus of Control Scale	Multifactorial Health Locus of Control Scale
Nowicki-Strickland Locus of Control Scale	Nowicki-Strickland Locus of Control Scale	Nowicki-Strickland Locus of Control Scale
Self Observation Scale	Self Observation Scale	Self Observation Scale

Table 3

Procedure



a. Measures Administered to Adults

Information was collected from the parents participating in the study before intervention, on five dimensions. These dimensions were 1) the parents' knowledge and understanding of the medical aspects of cystic fibrosis; 2) the nature of the family structure, organization, and values; 3) the parents' beliefs about their ability to control their own health; 4) the parents' beliefs about their ability to influence the reinforcement that they receive in general; 5) the parents' perceptions of their children's personalities.

After the intervention phase the above measures were repeated, with the addition of a detailed questionnaire which allowed the parents to evaluate many aspects of the group experience. The follow-up measures, administered approximately 6 months after the groups concluded, consisted of the original five measures, with the addition of a measure designed to tap parents' beliefs about their control of their children's health, developed too recently for the inclusion in the initial assessment.

All children over the age of 3 received the same four measures before the intervention, after the intervention, and at the follow-up data collection. These four instruments assessed; the child's knowledge of cystic fibrosis, his or her beliefs about control over his own health, beliefs about locus of control of reinforcement in general, and a measure of the child's own view of himself.

The instruments used to measure these various dimensions will be described below; copies of the scales may be found in the Appendix,

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Adult Cystic Fibrosis Knowledge Questionnaire:

In order to assess the parents' understanding of cystic fibrosis, a questionnaire was administered which was designed specifically for the present study. The questionnaire, which consists of both true-false and multiple choice questions, is presented in Appendix E. It was designed to tap the parents' grasp of a body of knowledge felt to be essential for them to be able to manage their child's illness adequately. Thus, it includes questions both on the pathophysiology of the disease and on principles of care.

Moos Family Environmental Scale:

Family functioning was assessed through the Moos Family Environment Scale, which was designed to assess the functioning of families on several dimensions (Moos, Insel and Humphrey, 1974). These included interpersonal relationships among family members, the basic organizational structure of the family, and the values which are encouraged. The instrument was developed using the general theoretical formulation of environmental press, and was developed and validated on a wide variety of populations. The authors of the scale have labeled 3 superordinate dimensions, each of which contains several subscales. In using the scale, each of these subscales is scored and evaluated separately, although a profile can be prepared presenting all subscales. These dimensions and subscales are as follows; three Relationship dimensions, including Cohesion, Expressiveness, and Conflict; five Personal Growth dimensions, including Independence, Achievement

Orientation, Intellectual-Cultural Orientation, Active Recreation Orientation, and Moral-Religious Emphasis; and two System Maintenance dimensions, including Organization and Control. The precise meaning of each subscale is relatively easily derived from the title; for example, Cohesion is defined as "the extent to which family members are concerned and commited to the family and the degree to which family members are helpful and supportive of each other" (page 4).

Locus of Control:

The construct of locus of control of reinforcement, the individual's perception of whether he himself, or some external force, has control over the events in his life and the reinforcement he receives, is an extensively researched and documented one (Rotter, 1966). Because of our clinical perception that many parents of chronically ill children feel helpless in the face of the onslaught of their children's disease, and since a major goal of much of the work done with these families is to increase the parents' perception of having control over the situation, this was felt to be an important area to assess. The instrument used to measure locus of control in the parents in this study was the Nowicki-Strickland Internal-External Locus of Control Scale (Nowicki and Duke, 1974). The scale consists of 40 items scored in either the internal or external direction, and has good reliability and validity characteristics.

Health Locus of Control:

Because of the critical importance of parents' perceptions of the degree of control they can exert over health issues, and because one of

the goals of this project was to increase this perception, beliefs as to whether or not one's health was determined by one's own behavior was specifically measured. The Multidimensional Health Locus of Control (MHLC) Scales was utilized (Wallston, Wallston, and DeVellis, 1978). This scale refines the concepts involved in the original locus of control research by accepting the argument that internal and external beliefs are in fact orthogonal, and that it is important to study individual's expectations about the role of fate and chance separately from internal control and control by others. Because of the great emphasis on powerful others frequently found in the health field, the "powerful others" dimensions seems especially important. The MHLC, thus, yields three separate scores: A Powerful Others Scale, an Internal Scale, and a Chance Scale. The instrument consists of 18 items which are scored a 6-point Likert-type format.

Child Personality Scales:

The final dimension upon which parents were assessed during all three data collection times was their perception of their children's personality characteristics and competence. The instrument used was the Childhood Personality Scale (Dibble and Cohen, 1974), developed at the National Institute of Mental Health. While designed for the original purpose of studying personality development in twin children, this measure has several major advantages for such a study as the present one. It does not focus primarily on psychiatric symptoms, but is weighted evenly with regard to both positive and negative chacteristics, thus avoiding the implication that psychological problems are

expected. It is applicable to a wide range of ages, from infancy to adolescence. Finally, it is multifactorial, providing for separate scores on the following five dimensions: Attention (extremely inattentive - extremely good attention); Behavior Modulation (hypoactive to hyperactive); Sociability (extroversion to introversion); Zestfulness (extreme zestfulness to apathetic passivity); Verbal Expressiveness and Mood (quiet and moodiness to talkativeness). Four carefully selected items comprise each factor, each of which is assessed using a seven - point Likert type scale. Thus, a child attains a score ranging from 0 to 24 of each of the five factors. The maximum score of 24 for each of the five factors described above corresponds with the following behavioral characteristics (referring to the five factors listed above): extreme attentiveness, hyperactivity, marked introversion, extreme apathy, and talkativeness and positive mood.

Child Improvement Locus of Control Scale:

After the first two data sets were collected, a new scale became available for preliminary use. This scale, designed to assess the degree to which parents feel that they have control over their child's health, is directly analogous to the Health Locus of Control Scale described above, except for its focus on the parents' perceptions with regard to their child's health (DeVellis, Revicki and Bristol, Ref. Note 2). This scale was inserted in the followup test packet for exploratory purposes, and with the hope that it would provide further information of the characteristics of the parents in general and the differences between the groups that had received the two interventions

in particular.

The theoretical basis, structure and format of this questionnaire are essentially the same as the Health Locus of Control Scale described previously.

Parent Education Group Evaluation Questionnaire:

During the posttest data collection period, immediately after the conclusion of the fourth group, all parents completed a detailed evaluation of the group experience designed specifically for this project. The questionnaire consisted of several parts. The first part was essentially a replication of the needs assessment survey done prior to the formation of any groups in the Cystic Fibrosis Clinic. It asked parents which areas of information they felt were important to them, how well they understood these areas a year ago and at present, their general preference about format of groups and other sources of information. The second part allowed the parents to rate each of the sessions separately, as to material presented, method of presentation, and quality of group interaction, on a seven point Likert Scale from "not helpful" to "very helpful." The parents in the Cognitive groups thus rated four sessions, that is, each of the four medically oriented presentation; the parents in the Cognitive-Communication group rated eight sessions, each of the four medical sessions and each of the four communications skills sessions. Finally, the parents were asked to rate the overall group experience on a seven point scale, and to answer open ended and check list types of questions on how the group meetings could be improved.

b. Measures Administered to Children

During each of the three data collection periods, each child age four and over was administered four instruments. Two of these, the Health Locus of Control Scale for Children and the Nowicki-Strickland Locus of Control Scale adaptations for children, are directly comparable to adult measures and thus will not be described in further detail.

A third measure, the Children's Cystic Fibrosis Knowledge Questionnaire, was also developed especially for this study. Again, the questionnaire itself and the rules for scoring are found in Appendix F. This scale differs from the adult scale not only in the phrasing of the questions and the material covered, but also in that it directly taps the child's understanding of basic anatomy and physiology, since the literature indicates that children's knowledge in this area proceeds according to a regular developmental sequence (Gellert, 1978, Whitt, et al., Ref. Note 3) from conceptualizing the body as only a bag of bones and blood to relatively complete and sophisticated understanding in adolescence. The children were presented with an empty mannequin outline, and colorful paper "body parts", designed by a medical illustrator for this study. They were first asked to label the parts, and then to place them in their proper position in the mannequin, and finally to identify them by function. Although the emphasis was on body parts relevant to cystic fibrosis, other parts important to children, such as the heart and the brain, were also included.

Finally, the children all completed the appropriate Self Observation Scale (Stenner and Katzenmeyer, 1979). This scale is a direct

self report imstrument with empirically determined scales that "measure the way children and adolescents perceive themselves and their relationships to peers, teachers, and school" (Stenner and Katzenmeyer, 1979, page 3. Primary Level, intermediate level, and junior and senior high school levels of the scale are available. The primary level measures the dimensions of Self Acceptance, Social Maturity, School Affiliation, and Self Security. The intermediate and high school level of the scale add dimensions of Social Confidence, Teacher Affiliation, and Peer Affiliation.

3. Content of Groups

The Cognitive portion of the material was presented to each group separately by four invited speakers. The information presented by the speakers, and their mode of presentation, was essentially identical for the two groups. After the invited speaker left the Cognitive group, the CF clinic nurse clinician led a factually oriented discussion of the material that had just been addressed. Such a discussion was not available to the Cognitive-Communication group, since they received the material during the second half of their group meeting.

The Cognitive presentations all followed a lecture format, with a blackboard available. The information was designed to be useful to parents who had some background in cystic fibrosis, but who may never have had a systematic, formal presentation of the more technical aspects of the disease and its therapy. The information covered in the four groups is described below.

General Disease Process: The first session, on general medical infor-

mation about cystic fibrosis, was presented by the Director of the North Carolina Memorial Hospital Cystic Fibrosis Center, a pediatrician experienced in lung disease in general and cystic fibrosis in particular. He reviewed pulmonary and digestive anatomy, and the pulmonary and digestive pathophysiology. Abnormalities of secretions in the lungs, digestive tract, and skin were discussed. Next, the history of defining and furthering our understanding of cystic fibrosis was reviewed. Problems in reproduction specific to both the male and female cystic fibrosis patient were covered. Finally, recent advances in research were covered, including both increases in life span due to more sophisticated use of antibiotics, and recent work in carrier detection.

Genetics: The second session, covering genetic aspects of cystic fibrosis, was taught by a masters-level genetics counselor employed by the Department of Pediatrics. She described the nature of the carrier state, the mechanism of transmission of cystic fibrosis, and the problems inherent in detecting carriers. The incidence of the disease in the general population, in siblings of known carriers, and in children of cystic fibrosis patients was discussed. Finally, the nature of genetic transmission of traits in general was discussed, and the likelihood that most individuals carry various abnormal genes was emphasized.

Nutrition: The session on nutrition for children with cystic fibrosis was led by a hospital nutritionist with extensive special interest in and experience with cystic fibrosis. Her presentation began with a discussion of the digestive system in general, and the role of enzymes in digestion. She then covered the replacement of enzymes, and the

mechanism by which this improves nutrition. Methods of increasing caloric intake without increasing fat intake were suggested, and special formulas for infants were described. Finally, she gave each group member a copy of a low-fat cookbook that she had developed especially for her patients.

Physical Therapy: The fourth session, on the role of physical therapy in cystic fibrosis, was led by the chief of the hospital's Pediatric Physical Therapy service, who was known to many of the parents from earlier instruction in postural drainage. She reviewed the anatomy of the respiratory tract and the mechanism by which physical therapy is beneficial. Because the parents were in general quite familiar with the details of postural drainage treatment, she emphasized the value of other forms of exercise in the child's everyday routines in helping to expand pulmonary functioning. She also described the potential usefulness of physical therapy boards, and presented a handout and discussion on how to build and use such a board.

4. Communication Material

The Cognitive Communication group received four sessions of instruction in principles of parent-child communication, during the period of time in which the Cognitive group was receiving the medically oriented lecture. These sessions were led by a masters' level social worker experienced both in parent counseling and parent group work, who was also known to the parents as the cystic fibrosis clinic social worker. The curriculum for these groups closely followed the work of Thomas Gordon as described in his Parent Effectiveness Training books and

manuals (Gordon, 1970), with some modifications to make the material more directly applicable to parents of a chronically ill child. Each of the four sessions focused on a central theme in his program, and included experiential techniques such as role-playing and discussion in dyads, in addition to didactic presentation. Reading assignments and "homework" were given out at the end of each session to reinforce the material that had been covered.

Problem Ownership: The first session set the stage for viewing children's behavior from the perspective advocated by Gordon, that is, all behavior can be looked at as being either acceptable or unacceptable; different behaviors may be acceptable or unacceptable depending on such factors as the individual's age, the time of day, and other activities occurring at the same time. The concept of problem ownership was then introduced, emphasizing the point that unless the behavior has been classified by the parent as "unacceptable", then the parent does not own the problem. Thus, many worries, concerns, and complaints offered by a child may actually constitute the child's problem rather than the parents' problem. It was felt that this concept would be crucial in helping parents to allow children to "own" and solve their own problems with the parents' help and support as needed and appropriate, but without the parents becoming overly involved.

Active Listening: The second session began with a review of problem ownership, making the point that when the parent has determined that the child indeed owns the problem, then there are various possible means available to the parent to be helpful. "Advice" and its perils

were discussed along with the general concept of what kinds of communication constitutes a "road block" that inhibits rather than facilitates further communication. These were related to passive and active listening, focusing on the importance of listening to one's child or to other family members as part of developing good communication skills. "Active listening" was discussed in detail beginning with the importance of differentiating words used from underlying meaning. The process of receiving a verbal or nonverbal message, "decoding" the message, then "checking out" one's perception of the message, and finally receiving the speaker's confirmation or clarification was described and practiced. The effects of such a process were described; that is, confusion about meaning is avoided, judgmental or directive statements are avoided, and the child experiences an increase in his feeling of self-worth as a result of being carefully attended to.

"I" Messages: The general concept of verbal and nonverbal messages was covered, and the fact that children respond less to what parents say but more to how they say it was emphasized. Next, the concept of "You" messages (judging, ordering, blaming, and labeling statements) and of "I" messages (descriptions of behavior, messages about one's own feelings and the effect that behavior has on one) was described in detail. Extensive practice in giving "I" messages both to one's children and to other family members and friends was carried out, and the fine points of giving "I" messages to very young children were discussed.

Problem Solving: In the fourth session, ways of facilitating change as a response to a problem were reviewed. The options available -

changing the child, changing oneself, and changing the environment were discussed. Learning how to develop sensitivity to the child's needs in a problem situation was emphasized. Finally, systematic techniques for mutual problem solving, using brainstorming, active listening, and "I" messages to make the process a mutual exploration, were described.

C. Results

The quantitative results of this study, which are given in detail in Tables 4-10, will be summarized here.

The results of the pretest data collection on the 18 individuals who began the study are presented in Table 4. As will be apparent from inspection of the means and standard deviations given for the questionnaires administered, this sample does not appear to differ strikingly from the general population. Population norms are given when available; the only significant differences from the norms shown by this population are on the scales of Moral-Religious Emphasis and Organization from the Moos Family Environment Scale. Given the relatively fundamentalist Southern culture prevalent in North Carolina, with its strong values on church, family, and community, this is probably not surprising and not unique to our sample.

The CF knowledge questionnaire results are interesting in that the parents missed, on the average, only three out of a possible 37 items on the test. Obviously, little room for measurable improvement on this scale was available.

While population norms were not available for the Child Behavior

Table 4

(Group 1 = Cognitive-Communication Group
Group 2 = Cognitive Group)

1. Pretest Scores

(Based on all 9 original subjects in each group)

Instrument	Mean and Standard Deviation, Combined Groups	Mean and Standard Deviation, Group 1	Mean and Standard Deviation, Group 2	Population Norms (When available)
[1]Nowicki-Strickland Locus of Control Scale	$\bar{x}$ = 31.7 s = 5.5	$\bar{x}$ = 31.3 s = 4.4	$\bar{x}$ = 32.0 s = 6.6	
[2]CF Knowledge Questionnaire	$\bar{x}$ = 34.5 s = 1.9	$\bar{x}$ = 34.7 s = 1.8	$\bar{x}$ = 34.3 s = 2.1	
[3]Moos Family Environment Scale				
Cohesion	$\bar{x}$ = 7.3 s = 2.1	$\bar{x}$ = 7.4 s = 2.3	$\bar{x}$ = 7.1 s = 2.1	$\bar{x}$ = 6.4 s = 1.9
Expressiveness	$\bar{x}$ = 6.5 s = 2.3	$\bar{x}$ = 6.7 s = 2.2	$\bar{x}$ = 6.3 s = 2.5	$\bar{x}$ = 5.4 s = 1.5
Conflict	$\bar{x}$ = 4.2 s = 2.6	$\bar{x}$ = 4.0 s = 2.9	$\bar{x}$ = 4.4 s = 2.3	$\bar{x}$ = 4.65 s = 2.05
Independence	$\bar{x}$ = 6.4 s = 1.8	$\bar{x}$ = 6.8 s = 1.7	$\bar{x}$ = 6.1 s = 1.9	$\bar{x}$ = 6.7 s = 1.2
Achievement Orientation	$\bar{x}$ = 5.8 s = 1.9	$\bar{x}$ = 6.1 s = 1.4	$\bar{x}$ = 5.6 s = 2.4	$\bar{x}$ = 5.6 s = 1.7
Intellectual-Cultural Orientation	$\bar{x}$ = 6.1 s = 2.2	$\bar{x}$ = 5.4 s = 2.5	$\bar{x}$ = 6.8 s = 1.7	$\bar{x}$ = 6.15 s = 1.98

Table 4 (continued)

Instrument	Mean and Standard Deviation, Combined Groups	Mean and Standard Deviation, Group 1	Mean and Standard Deviation, Group 2	Population Norms (When available)
Active-Recreational Orientation	$\bar{x}$ = 5.4 s = 2.8	$\bar{x}$ = 4.4 s = 2.5	$\bar{x}$ = 6.4 s = 2.8	$\bar{x}$ = 6.19 s = 1.7
[4]Moral-Religious Emphasis	$\bar{x}$ = 5.8 s = 2.3	$\bar{x}$ = 5.4 s = 2.1	$\bar{x}$ = 6.1 s = 2.6	$\bar{x}$ = 4.55 s = 2.15
[4]Organization	$\bar{x}$ = 6.6 s = 2.3	$\bar{x}$ = 6.6 s = 2.9	$\bar{x}$ = 6.7 s = 1.7	$\bar{x}$ = 5.3 s = 2.0
Control	$\bar{x}$ = 4.7 s = 2.3	$\bar{x}$ = 4.4 s = 2.6	$\bar{x}$ = 5.0 s = 2.1	$\bar{x}$ = 4.8 s = 1.84
[5]Multifactorial Health Locus of Control Scale				
Internal Control	$\bar{x}$ = 25.4 s = 4.97	$\bar{x}$ = 25.4 s = 4.5	$\bar{x}$ = 25.3 s = 5.8	$\bar{x}$ = 25.3 s = 4.6
[6]Powerful Others	$\bar{x}$ = 18.4 s = 5.5	$\bar{x}$ = 18.2 s = 7.2	$\bar{x}$ = 18.6 s = 3.2	$\bar{x}$ = 20.97 s = 5.5
Chance	$\bar{x}$ = 16.6 s = 6.1	$\bar{x}$ = 17.6 s = 6.9	$\bar{x}$ = 15.5 s = 5.2	$\bar{x}$ = 15.5 s = 5.2
[7]Child Behavior Checklist				
[8]Attention	$\bar{x}$ = 16.3 s = 4.1	$\bar{x}$ = 15.0 s = 4.7	$\bar{x}$ = 17.9 s = 2.9	
[9]Behavioral Modulation	$\bar{x}$ = 16.5 s = 4.2	$\bar{x}$ = 15.9 s = 4.9	$\bar{x}$ = 17.2 s = 3.4	

Table 4 (continued)

Instrument	Mean and Standard Deviation, Combined Groups	Mean and Standard Deviation, Group 1	Mean and Standard Deviation, Group 2	Population Norms (When available)
[10]Sociability	$\bar{x}$ = 5.2 s = 3.4	$\bar{x}$ = 6.4 s = 3.99	$\bar{x}$ = 3.7 s = 2.1	
[11]Zestfulness	$\bar{x}$ = 4.8 s = 3.3	$\bar{x}$ = 5.6 s = 4.1	$\bar{x}$ = 3.8 s = 1.8	
[12]Verbal Expressiveness	$\bar{x}$ = 18.0 s = 6.0	$\bar{x}$ = 19.0 s = 5.0	$\bar{x}$ = 20.8 s = 2.2	

[1]40 items. High score is internal.
[2]37 items. Score is number correct.
[3]9 items on each subscale. High score is stronger tendency in described characteristic.
[4]Total CF group score exceeds population norm at .05 level of significance (Two-group t-test)
[5]For each subscale, total score of 36 possible.
[6]Study sample differs from population norm significantly at .o5 level; two-tailed t-test, t = -2.54
[7]Child Behavior Checklist scores, when two parents filled out checklist, are based on the mean of the ratings of the two parents. Total score possible on each subscale is 30.
[8]High score indicates long attention span.
[9]High score indicates high activity level.
[10]Low score indicates tendency toward sociability.
[11]Low score indicates energy, zestfulness.
[12]High score indicates much verbal activity.

Checklist, it appears that parents rated their children in an intermediate range in terms of attention span and level of activity, but as being quite sociable, enthusiastic and zestful, and verbally expressive.

On the Multifactorial Health Locus of Control Scale, it was found that while the study families were almost identical to the population norms in their ascription of control over their health to internal and chance factors, they ascribed significantly less control over their health to Powerful Others, predominantly members of the health professions.

As may be seen in Tables 5 and 6, there was very little change on the measures collected from the pretest period to the posttest and follow-up periods, and the two study groups did not differ in the amount or direction of change. Thus, the measures selected failed to demonstrate differential effectiveness for the two group approaches utilized.

The Child Health Questionnaire, a new instrument currently under study by DeVellis et al., is presented in Table 7. The two groups did not differ in their pattern of ascribing control over their child's health to various sources, but they appear to see parental and professional factors as being of proportionately greater importance than chance or child related factors.

The data collected from the seven children old enough to participate are reported in Table 8. While the number of children in each intervention group and at each age level was too small to allow formal analysis, these data may be useful to investigators collecting similar data. Not surprisingly, there does appear to be a developmental trend

Table 5

2. Analysis of changes from Pretest to Post-test

2 - Tailed Mann-Whitney U Test on change scores ($T_2 - T_1$)

Instrument	Mean Change, Group 1	Mean Change, Group 2	Significance
Nowicki-Strickland Locus of Control Scale	2.88	-2.50	NS
CF Knowledge Scale	-0.63	0.63	NS
Moos Family Environment Scale (Selected Subscales)			
Independence	-0.88	-0.57	NS
Expressiveness	-0.38	0.14	NS
Control	-0.13	-0.14	NS
Cohesion	-0.50	-1.0	NS
Conflict	0.25	-0.57	NS
Health Locus of Control			
Internal Control	-2.63	1.57	NS
Powerful Others	0.13	0.17	NS
Chance	4.13	0.71	NS
Childhood Personality Scale			
Attention	-0.25	-0.38	NS
Sociability	0.75	1.75	NS
Verbal Expressiveness	0.38	-0.88	NS
Behavior Modulation	-0.50	-1.0	NS
Zestfulness	-1.75	-0.25	NS

Table 6

3. Analysis of Changes from Pretest to 6-Month Follow-up Test

2 - Tailed Mann-Whitney U Test on change scores

Instrument	Mean Change, Group 1	Mean Change, Group 2	Significance
Nowicki-Strickland Locus of Control Scale	-1.25	-0.75	NS
CF Knowledge Scale	-0.88	0.125	NS
Moos Family Environment Scale (Selected Subscales)			
Independence	-0.75	0.125	NS
Expressiveness	-1.125	-0.875	NS
Control	0.25	-0.38	NS
Cohesion	-0.125	-0.125	NS
Conflict	-0.25	-0.625	NS
Health Locus of Control			
Internal Control	0.625	-0.57	NS
Powerful Others	-0.50	0.857	NS
Chance	.125	0.43	NS
Childhood Personality Scale			
Attention	0.417	-0.600	NS
Sociability	1.5	0.7	NS
Verbal Expressiveness	-0.667	-2.2	NS
Behavior Modulation	-1.25	-3.1	NS
Zestfulness	1.25	0.00	NS

Table 7

4. [1]Results of Child Improvement Locus of Control Scale

(Administered at Follow-up Only)

Subscale (Locus of Control)	Means and Standard Deviations, Group 1	Means and Standard Deviations, Group 2	Significance
Parent	$\bar{x}$ = 28.25 s = 4.7	$\bar{x}$ = 27.75 s = 4.3	NS
Professional	$\bar{x}$ = 27.4 s = 6.35	$\bar{x}$ = 26.9 s = 4.9	NS
Chance	$\bar{x}$ = 22.9 s = 6.1	$\bar{x}$ = 18.5 s = 7.3	NS
Child	$\bar{x}$ = 19.25 s = 4.3	$\bar{x}$ = 23.4 s = 7.8	NS

[1]Possible score of 36

Table 8

Data Collected from Children

(Reported by Subject)

Instrument	Subject Number	Age	Sex	Pre-test	Post-test	Follow-up
[1]Children's CF Knowledge Test	2	4	F	4	5	6
	6	4	M	4	--	--
	1	5	F	4	7	13
	7	5	F	21	23	21
	5	6	F	12	13	9
	8	11	M	28	28	28
	3	12	F	21	27	28
	4	14	M	29	29	30
[2]Children's Health Locus of Control	2	4	F	8	9	14
	6	4	M	9	--	--
	1	5	F	5	9	6
	7	5	F	12	13	13
	5	6	F	7	13	6
	8	11	M	17	15	18
	3	12	F	20	20	20
	4	14	M	20	17	20
[3]Preschool and Primary Nowicki-Strickland Locus of Control Scale	2	4	F	13	12	19
	6	4	M	13	--	--
	1	5	F	15	16	7
	7	5	F	14	12	11
	5	6	F	16	13	18
[4]Children's Nowicki-Strickland Locus of Control Scale	8	11	M	27	34	35
	3	12	F	29	31	34
	4	14	M	33	34	38
Self-Observation Scale	2					
	6					
	1					
	7					
	5					
	8					
	3					
	4					

[1]Possible score of 30.
[2]Possible score of 20; high score is internal.
[3]Possible score of 26; high score is internal.
[4]Possible score of 40; high score is internal.

in knowledge of cystic fibrosis, with the striking exception of a very bright and quite ill five year old who scored at a level comparable to the pre-adolescents in this study. Other than that, it is difficult to draw generalizations from this amount of data. Table 9 reports the responses given by parents to the evaluation questionnaire administered after the intervention. The frequency with which parents reported needing information about a variety of areas in the past year may be noted, in addition to their ratings of the adequacy of their knowledge in these areas a year ago and currently. The parents rated their current understanding of these issues as being significantly better than their understanding a year ago.

While the numbers are too small to allow for statistical comparisons, it appears that the parents are divided in their preferences among the study intervention series, discussions with staff, and earlier parent group experiences. However, they overwhelmingly rated the current group series as both interesting and useful.

When asked to cite the professionals and other sources of information that were most helpful to them, the families cited the clinic physicians and nurses most often, closely followed by "other parents". However, a variety of other resources were also seen as useful by significant numbers of individuals.

When asked in which areas they desired more counseling, parents cited the needs of siblings most often, but also mentioned the issues of death and dying and child behavior as being frequent concerns.

The two groups of parents indicated a desire for further opportuni-

Table 9

Parents' Responses to Evaluation Questionnaire, Part I

(Administered with Post-Test)

Questions 2, 3 and 4

Areas Related to Cystic Fibrosis	Information Needed in Past Year (Number of Citations)	[1]Ratings of Understanding a Year Ago		Rating of Current Understanding	
		A lot/some	Little/none	A lot/some	Little/none
Dietary Management	11	13	5	17	1
CF Research	11	14	4	17	1
Life Expectancy	10	13	3	16	2
Genetics	9	15	2	18	0
Physical Therapy	9	15	2	18	0
School Adjustment	8	11	6	17	0
Discussing CF With Child	7	8	8	16	2
Normal Child Development	3	15	2	17	0
Dating and Marriage	2	6	11	13	4
Jobs and Careers	2	7	10	14	4

NOTE: Some subjects left certain questions blank; thus totals do not always equal 18.

[1]Comparison of Ratings of Understanding; One Year Ago Versus Current, with Two-tailed Mann-Whitney U Test is significant at .05.

Table 9 (Continued)

Question 5

Preferences for information sources, by group

	Group 1	Group 2
Current group series	3	5
Informal discussions with staff	5	1
Previous parent groups	1	3

Question 6

Opinions of current group series

	Group 1	Group 2
Interesting, not useful	1	0
Interesting, useful	7	8
Not useful or interesting	1	0
Other ("Didn't go far enough")	0	1

Question 7

Most Useful Resources	Number of Citations
Clinic Physician	17
Clinic Nurse	15
Other Parents	13
Physical Therapist	11
Psychologists	9
Social Workers	6
Nutritionists	6
Local Physician	5
CF Foundation Staff	2
Play Therapists	1
Other (CF Foundation Chapter Meeting)	1
Local Nurse	0

Table 9 (Continued)

Question 8

Areas in which parents desire more counseling

Area	Number of Citations
Needs of siblings	10
Death and dying	8
Behavior	7
Dietary management	6
Jobs and careers	5
Physical therapy	5
Medications	5
Genetics	3
Dating and marriage	3
(Written-in): Psychological needs of CF child	1

Question 9

Further opportunities desired

Format	Number of Citations	
	Group 1	Group 2
Group decisions	7	7
Individual discussions	2	3
Other (written in): Workshops including CF parents	1	0

ties for group discussion at the same frequency.

The parents' actual evaluation of the study groups is found in Table 10.

Looking first at ratings of the Cognitive group material (the lectures on medical, genetic, nutritional, and physical therapy issues in cystic fibrosis), the ratings were generally very high. Although the two groups actually received the same presentations, the Cognitive-Communication group rated these portions more highly at a statistically significant, although numerically fairly small, level.

The parents in the Cognitive-Communication group tended to give intermediate ratings to the communication material. Their ratings of this material was, overall, significantly lower than their ratings of the cognitive material.

Despite these differences, however, the ratings of the total group experience made by the two groups did not differ.

Finally, it was found that, in equal numbers, the parents in both groups would have preferred more parental participation and leadership, more focus on specific problems, and perhaps somewhat more technical information.

D. Discussion

Many of the results of the study were unexpected. While the study did not demonstrate, as expected, that including a communications component in parent group work would improve specific aspects of functioning in families of children with cystic fibrosis, the results have a number of theoretical and clinical implications.

Table 10

Parents' Responses to Evaluation Questionnaire, Parts II and III

Part II

Questions 1-4

[1]Mean Ratings by Group of Cognitive Material

	Medical Aspects		Genetics		Nutrition		Physical Therapy	
	Group 1	Group 2	Group 1	Group 2	Group 1	Group 2	Group 1	Group 2
Material Presented	6.1	6.0	5.9	6.0	5.8	5.2	6.8	5.3
Method of Presentation	6.5	5.4	5.0	5.7	6.8	5.2	6.8	5.3
Group Interaction/ Discussion	5.5	5.3	5.0	5.1	6.0	5.3	6.3	5.3

[1]Rated on scale of 1 = Not Helpful to 7 = Very Helpful

Cumulated Mean Ratings of Cognitive Material

Group 1	Group 2
6.05	5.41

Mann-Whitney U = 110

Significant at .05

Table 10 (Continued)

Questions 5-8

Group 1 Mean Ratings of Communication Material

	Problem Ownership	Active Listening	I-Messages	Mutual Problem-Solving
Material Presented	5.1	4.1	5.2	4.0
Method of Presentation	4.6	3.6	4.2	4.4
Group Interaction/ Discussion	5.6	4.1	4.8	5.5

Group 1 Cumulated Mean Ratings of Cognitive Versus Communication Material

Cognitive Material	Communication Material
6.05	4.61

Mann-Whitney U = 135

Significant at .05

Table 10 (Continued)

Part III

Question 1

Rating by Group of Total Series

Group 1	Group 2
5.13	5.78

Mann-Whitney U = 27

Not Significant

Question 6

Preferences for Changes in Group Format, By Group

Suggested Change	Number of Citations	
	Group 1	Group 2
More parent participation, leadership	5	6
Less parent participation, leadership	0	0
More focus on specific problems	5	6
Less focus on specific problems	1	0
More technical information	4	4
Less technical information	0	0
Larger groups	0	2
Smaller groups	1	0

1. Objective Test Data

To begin with the results of the parental pretest measures, it was noteworthy that there were so few differences found between the study sample and general population norms (Table 4). Despite the somewhat dismal impression gained in the literature, it appears that, on this group of paper and pencil measures, parents of CF children report relatively typical views of their families' functioning and their children's adjustment. The differences that emerged on the dimensions of Moral Religious Emphasis and Organization on the Moos Family Environment Scale, are more likely an artifact of the cultural milieu from which the families were drawn, than indicating anything particular about families with a chronically ill child. The excellent performance exhibited by the parents on the CF knowledge questionnaire is indicative both of the effectiveness of previous efforts at both individual and group parent teaching carried out in the clinic, and also a positive sign in terms of the families' coping abilities, since even the best teaching may be ineffective if individuals are too emotionally stressed to learn. (See Table 4)

It is most interesting that the study sample viewed Powerful Others as having less control over their health than did the population norms. (See Table 4) Although the possibility cannot be discounted that this finding is an artifact of chance, due to the large number of scores, it seems quite comprehensible if one notes that parents are told repeatedly that while the physicians and nurses will do their very best to help care for their child, parents themselves will have responsi-

bility, and that there will be major limits to what anyone can do in the long run. Parents may well have internalized the message that the power of health care professionals is indeed limited to a greater extent than the general public, who may retain more fantasies about the omnipotence of such individuals. If that interpretation is correct, it may be an indication of the degree to which the families are, at least in some respects, able to face rather unpleasant realities.

While it is impossible to rule out the influence of denial and wishful thinking, it does appear that the parents in this study have quite a positive view of their children. Their tendency to perceive their children as both sociable and energetic may or may not be followed up, in individual cases, by their being able to grant their children age appropriate degrees of autonomy and freedom to interact with others, but certainly can be seen as a positive first step.

Perhaps the least expected finding was the lack of demonstrable differences between the two experimental groups resulting from the intervention (Table 5). Not only did the groups not differ, but there was essentially no demonstrable change in the group as a whole from pretest to posttest to follow-up. As in all cases of failure to reject the null hypothesis, we cannot be sure whether this signifies a weak intervention, poorly selected dependent variables, insensitive measures, or an incorrect initial hypothesis. It is quite possible that four 2-hour group meetings, in the course of continuous, long-term clinic contacts involving a variety of individualized interventions, have little relative impact. However, in light of the findings

on the parent evaluation forms that the group receiving both the Cognitive and the Communication material preferred the Cognitive material, another explanation is possible. It may be that the Communication group experience, which in fact contained many elements found in process therapy groups, i.e. role playing, examination of one's own behavior, and other experiential interactions, was inappropriate for a group of individuals whose lives may be seen as requiring relatively continuous coping with crisis. If families of children with chronic illness are conceptualized as being in a state of vigilance and preparedness for emergency, then an experience which focuses on specific interpersonal interactions unrelated to the overriding stress may be difficult to attend to and to integrate. Given the marked enthusiasm shown by both groups for the Cognitive material, despite the frequency with which these families are exposed to such material, this explanation appears to have credence. There is no way to evaluate the possibility of the potentially greater impact of the Cognitive material using this study's questionnaire, however, because of the initially high scores received by most parents. In order to show any significant improvement, the families would have had to achieved perfect scores the second time. However, the parents' subjective reaction to the cognitive presentations suggests that this material met a more urgent, felt need and supported current coping mechanisms more effectively than did the more process-oriented abstract communications curriculum. It is interesting that this appears to be the case despite, or perhaps because of, the affect-laden nature of the disease-related material.

Turning briefly to the results of the Child Improvement Locus of Control Scale, further work on this instrument will be necessary before it is possible to determine whether the particular pattern of results obtained is unique to families of children with chronic illness (see Table 7). However, it may be encouraging that parents perceive both themselves and professionals as being effective agents of control over their children's health. In the case of cystic fibrosis, this perception may not be as realistic as a perception which places greater power in the hands of such chance factors as the severity of the disease and the occurence of infection, but given the tremendous impact of effective parent behavior on the quality of life of many of these children, such a perception may be a positive force. Related to this question, the parent evaluation questionnaire, provided much useful information on parental perceptions about areas of need and competence with regard to cystic fibrosis. It is rather striking that parents cited much current concern over such issues as dietary management, cystic fibrosis research, and life expectancy, while saying that in the <u>future</u> that they would like more counseling on the needs of siblings, death and dying, and child behavior (see Table 9). Obviously, counseling that focuses too heavily on either biomedical issues or psychosocial issues will fail to meet the needs of these parents. They give us clear indications that both these areas are of great concern to them, although they perhaps need to feel comfortable and well informed with the day-to-day management and medical issues before they can turn to more ambiguous and emotion-laden topics.

In terms of the overall clinic program, it is extremely encouraging to see the marked level of improvement with which parents retrospectively credit themselves in their understanding of important areas related to their child's disease (see Table 9). Unfortunately, it is not possible to tell from this data whether these improvements were primarily perceived as being due to the current group experience or to information garnered from a variety of sources over the year. Some of the most marked increases were in such psychosocial issues as discussing CF with one's child (an increase from 8 to 16 in parents rating themselves as knowing "a lot or some"). However, somewhat fewer parents had originally rated themselves as having much knowledge in the psychosocial areas, so this apparent trend may be an artifact of the starting point. However, it is clear from the data that a sizeable majority of the parents rate themselves as having "a lot" or "some" understanding of all of the CF related areas questioned.

As indicated earlier in this discussion, the parents used several opportunities for rating the overall group experience and their preference for further experiences to indicate a significant amount of satisfaction with the group experience and approach (see Tables 9 and 10). Their consistent endorsement of more groups and their high overall satisfaction ratings for the groups are clear mandates for this general approach to parent support and education. However, their tendency to rate the communication information less highly than the cognitive information (see Table 10), combined with the failure to demonstrate changes on the psychosocial measures selected to try to

demonstrate the groups effectiveness, gives an unmistakable message that these parents feel the need for concrete, directly disease-related material to help them master their day-to-day challenges, rather than more general training in parenting and communication skills. Despite the great popularity that Gordon's work has achieved with the general public, it may have less relevance to families for whom the issue of raising a responsible adult is far less salient than the concern about helping a child live through the next year. This outcome is consistent with McCollum and Gibson's (1970) impression that parents in groups maintained limits on the depth of exploration permitted.

With regard to the format selected for the groups, the parents seem generally satisfied, but clearly indicated their preference for more parental interaction. As several parents remarked, one of the best parts of the program was the chance to sit and have lunch with other parents in a relaxed atmosphere. In a sense, the desire for more parental leadership and involvement contradicts the stated need for disease-related cognitive information; however, it is not difficult to see how both needs coexist. Perhaps the high rating given to the Cognitive group is due in part to the degree to which these two values were combined, in that a structured didactic presentation was then followed by informal discussion with much parental participation. This format may have much promise, since it allows not only for transmission and processing of information, but also for expression of other related concerns that may emerge after the need for concrete information is to some extent satisfied. It should also be noted that this multifaceted and somewhat con-

tradictory view of appropriate goals and formats for the group expressed by the parents is in line with the picture given by the literature of a number of group approaches, with no consensus on when particular approaches are appropriate.

2. Clinical Data

Turning from the quantitative data to more general clinical impressions, much was learned about the feasibility of such a program and its appropriateness for a wide variety of participants. It appears that while groups held on non-clinic days are possible, they would not be likely to succeed in the absence of such inducements as travel funding in a geographic region where families would have to travel any distance. On the other hand, there is a great deal to be gained from having consistent group membership, as parents subjectively reported pleasure in getting to know individual members of the group and in feeling increasingly comfortable with them. Perhaps the ideal situation is one where children who are seen in clinic at similar intervals can be scheduled to come on the same clinic days, so that groups may be held during clinic days and at the same time have consistent memberships. This is in fact what is being done at the present time at North Carolina Memorial Hospital.

It was also interesting that, based on clinical impressions, low educational level and socioeconomic status was not a barrier to high levels of group satisfaction and participation, and higher levels did not guarantee this. Some of the professional families were invaluable resources to the groups and themselves expressed great satisfaction

with them, while others had a great deal of difficulty in integrating some of the concepts for emotional rather than intellectual reasons, and found the groups somewhat stressful for that reason. While it was clear that the complexity of the information was adequate for most of the families, although some of them would have wished for even more technical detail, it was quite possible to achieve this level of satisfaction without causing great confusion in less well educated individuals. Parents will certainly differ in the endpoints that they reach in their search for knowledge, but they appear to have more commonalities than differences in their need for basic information regarding their child's disease and treatment. Clear, well organized presentations by knowledgeable and relaxed group leaders can certainly be successful even with a very heterogeneous audience. Another factor that should be mentioned is what might be called the "appreciation effect". The parents repeatedly expressed their gratitude for the effort the the clinic staff was going through to provide such a program for them; this gratitude certainly may have resulted in inflated overall evaluation scores. On the other hand, the groups appeared to convey an important message to the parents about the clinic staff's concern with making them fully involved and informed participants in their child's care. The message to professionals may be that as we slowly refine our skills in this area, families may be more tolerant of our imperfections than are we ourselves, since they perceive the intentions and values that underlie the efforts. Another clinical impression that was somewhat surprising to the project staff was that current

severity of disease did not seem to have as much impact as would be expected on the parents' response to the groups. While it did complicate the data collection, since some children had taken marked turns for the worse by the time the follow-up data was collected, severity of illness generally did not interfere with parents' attendance at or participation in the groups. In fact, several parents came down from their child's hospital room to attend the groups when the child was hospitalized during the study period. There was perhaps a greater sense of urgency in the questions of the parents of the sicker children, and less tendency to sit back and take an observer role, but in general it appeared that pre-morbid personality factors had accounted for more of the variance than did severity of illness. On the basis of our experience, then, there is no reason to exclude families of even relatively sick children from such experiences.

Finally, it should be noted that the number of children in the appropriate age range available for interview at the time of the study was disappointingly small, and that our inability to analyze this portion of the data constitutes a weakness in the study. Similar studies with access to much larger groups of children would be most beneficial, since the degree of indirect impact on the child should be an important dependent variable in assessing such intervention techniques. However, it was our impression that the measures utilized with the children were potentially quite useful, and that the child's CF knowledge questionnaire was both attractive, comprehensible to a wide age range, and has the potential to provide a great deal of important

information. The present study may be considered a pilot test of this technique, and its use with other populations is strongly encouraged.

V. Summary and Future Needs

This report has described and evaluated two group approaches to supportive intervention with families of children with cystic fibrosis. On the basis of the data and clinical impressions reported, it is clear that group approaches have a great deal of potential usefulness and are perceived very positively by parents. It also emerged that a concrete, cognitive disease-related focus to the groups was preferred by the parents over a more interpersonally oriented approach, but that differential effectiveness could not be demonstrated. At the same time that parents desired significant amounts of technical information, they also expressed a preference for large amounts of parental participation and interaction. Thus, professionals leading or sponsoring such groups have a dual challenge to meet. As a result of these findings, it is recommended that an approach that combines presentations by knowledgeable individuals on disease-related subjects be combined with ample opportunity for group discussion and processing. The evidence suggests that if a group series can be continued long enough so that the parents develop a sense of command of the bio-medical aspects of cystic fibrosis, they will express increasing interest in issues related to the psychological functioning of their child and family and show increasing ability to utilize information in this area.

Future Needs

A number of interesting issues are raised by these findings which stimulate a need for further investigation. First, the use of group self-help approaches is itself still in its early development and must bear more vigorous scrutiny and investigation before broad clinical application is undertaken. This may be especially true where the self-help focus is upon the families of patients and not the patients themselves since more resistance to the intrusion into personal privacy may be present under these circumstances. Clinical wisdom gained from populations of neurotic adults with long-term adjustment problems may not be directly transferable to populations of adults who perceive themselves as normal except for a specific life crisis. Furthermore, as in the present study, it is not often practicable to identify precisely who make up the functional family unit nor is it always possible to include them all in treatment. A second issue is the lack of current technical capability to adequately isolate and measure valid and reliable indices of psychosocial functioning in families. Our study employed "state-of-the-art" psychological instruments to monitor family processes but still we observe basically no change in pre- and post-treatment measurements. While there are certainly other explanations for this lack of apparent change it certainly behooves future investigators to require the most rigorous standards of their measurements techniques. More specifically the use of "tailor-made" instruments such as the Knowledge of CF questionnaire specially devised for this study, and the Parent Education Evaluation Questionnaire, offer more specific

assessment of clinical changes in special situations such as clinical investigations of this kind.

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APPENDICES

Appendix A: Recruitment Letter and Information for Subjects

Appendix B: Consent Form

Appendix C: Childhood Personality Scale

Nowicki-Strickland Locus of Control Scale

Multifactorial Health Locus of Control Scale

Child Improvement Locus of Control Scale

Appendix D: Parent Education Group Evaluation Questionnaire

Appendix E: Basic Knowledge of Cystic Fibrosis (Parents)

Appendix F: Children's CF Knowledge Questionnaire

Manual for Children's CF Knowledge Questionnaire

Appendix G: Children's Nowicki-Strickland Locus of Control Scale

APPENDIX A

Recruitment Letter and Information for Subjects

THE NORTH CAROLINA MEMORIAL HOSPITAL

The University of North Carolina

AT

CHAPEL HILL

27514

Dear Parents:

Over the past three years, we have been involved in group work with parents of children with cystic fibrosis to help them deal with the impact of the disease on the children and family. As some of you know, we have asked you for feedback and suggestions on the effectiveness of our efforts. Using your ideas and our experiences, we have developed some programs for parents, and have received funding from the National Cystic Fibrosis Foundation which will help us learn more about the usefulness of these programs.

Our plan is to offer a series of four group meetings this fall, to be directed and organized by the staff of our Cystic Fibrosis Center. Medical and genetic aspects of cystic fibrosis will be covered, along with emotional and developmental issues associated with this disease. These group sessions will not be a part of our regular Cystic Fibrosis Clinic and are not offered to substitute for any part of the regular medical care your child is now receiving. We will also be asking you and your child to fill out some questionnaires before and after the sessions to see how effective they are.

Some of you have already participated in group meetings at the clinic. However, we hope that the programs to be offered as part of this project will also be helpful in providing new information and ideas. In addition, because these meetings will be held on Saturdays, separate from regular clinic visits, we plan to provide travel funds and to compensate you for your time using the funds provided by the CF Foundation.

Please complete the questions below and return the form in the enclosed self-addressed and stamped envelope. If you have further questions, we can be reached during regular office hours. Thank you for your interest.

Yours sincerely,

Brian Stabler

Brian Stabler, Ph.D.
Associate Professor
Departments of Psychiatry,
Pediatrics and Family Medicine
(919) 966-2166

Gerald W. Fernald

Gerald W. Fernald, M.D.
Professor
Department of Pediatrics
Cystic Fibrosis Center Director
(919) 966-4303

BS:GWF:lr

Are you willing to participate in the parent education program as described in the letter? yes _____ no _____

Would you require baby-sitting services if the meetings were held in Chapel Hill? yes _____ no _____

Name _____

Address _____

_____

Telephone _____

Children's names _____ Ages _____

_____ _____

_____ _____

THE NORTH CAROLINA MEMORIAL HOSPITAL

The University of North Carolina

AT

CHAPEL HILL

27514

Dear

We are delighted that you will be joining us for the Parent Education Group programs this fall. We expect that these groups will be useful to you as parents, and it will be helpful for us to have a chance to get feedback from you. The purpose of this letter is to provide you with the information you will need.

WHEN WILL PROGRAMS BE HELD?

Saturday, October 4, 9:30-3:00

Saturday, October 18, 9:30-12 noon

Saturday, November 8, 9:30-12 noon

Saturday, December 6, 9:30-3:00

(Note that the first and last meetings are longer, because we will be gathering information through various questionnaires to help us evaluate the usefulness of our programs.)

SHOULD I BRING MY CHILD WHO IS A PATIENT IN THE CLINIC?

If your child is 3 years old or older, please be sure to bring him or her to the first session, October 4, and the last session, December 6, since we will be doing questionnaires with the children as well.

Of course, we will have supervised baby-sitting for all ages available for each session, so feel free to bring any of you children whenever you wish.

WHAT IF ONLY ONE PARENT CAN COME FOR SOME OR ALL OF THE SESSIONS?

Feel free to participate anyway.

WHAT IF WE MISS A SESSION?

It is important to the study that each family attend all meetings unless it is absolutely impossible to do so.

WHAT IS THE COMPENSATION FOR PARTICIPATION?

$25.00 per family for each session attended, plus an allowance for gasoline or bus fare based on how far away you live from Chapel Hill.

WHERE SHOULD WE COME WHEN WE ARRIVE SATURDAY MORNING?

Come to the pediatric waiting area where you usually come for clinic visits. We will go upstairs to the 9th floor recreation area for the groups.

WHERE SHOULD WE PARK?

On the parking deck across from the hospital. Since Carolina has football games on many Saturdays it is best to arrive as early as possible in order to get a good parking spot.

WILL THERE BE ANY FOLLOW-UP TO THIS STUDY AFTER DECEMBER?

In about six months, we will ask you to fill out some more questionnaires to help us evaluate the long-term usefulness of our groups.

WHO SHOULD I CALL IF I HAVE QUESTIONS OR PROBLEMS?

Call Dr. Melissa Johnson, at 966-2166. Leave your number if she's not there.

Once again, we're so pleased that you will be able to participate. We all look forward to a very worthwhile experience. See you on October 4!

Sincerely,

Melissa Johnson

Melissa Johnson, Ph.D.
Parent Education Program Staff

MJ:lr

APPENDIX B

NORTH CAROLINA MEMORIAL HOSPITAL
Department of Pediatrics
Cystic Fibrosis Clinic Parent Education Program

I, _____ hereby agree to participate in a study entitled "The Effectiveness of Parent Education Groups in Families of Children with Cystic Fibrosis," and to allow my daughter/son _____ to be part of the same study.

I understand that the study will involve having my child and I fill out a number of questionnaires concerning feelings and ideas as well as facts about CF, on three separate occasions throughout the study. I further understand that I and my spouse will attend monthly group meetings to be held in Chapel Hill. The meetings will involve learning more about the medical background of cystic fibrosis and about how it is best treated. I understand that the study will be under the direction of Brian Stabler, Ph.D. and that I am free to withdraw my consent and discontinue my child's participation at any time.

In understand that I will gain an increased understanding of the medical management of cystic fibrosis and that it is expected that the study will produce a better understanding of how to manage the psychological and emotional aspects of cystic fibrosis. I also understand that the alternative method available is individual discussions and counseling with my attending physician. While no guarantee is given or implied, it is further understood that the study is expected to produce positive results in terms of my child's feelings of self-confidence and understanding of cystic fibrosis, and that no physical or emotional risks are expected.

I understand that Brian Stabler, Ph.D. and Gerald W. Fernald, M.D. are directly responsible for this project. Should I have any questions or complaints they may be contacted at any time. If I feel that there has been any infringement on my child's or my rights, I may contact the Chairman of the Committee on the Protection of the Right's of Human Subjects or any of its members. I understand that in the event of physical injury directly resulting from research procedures, financial compensation cannot be provided. However, every effort will be made to make available for me the facilities and professional skills of the University of North Carolina at Chapel Hill.

Date: _____ Signed: _____

Date: _____ Witness: _____

APPENDIX C

Childhood Personality Scale

Nowicki-Strickland Locus of Control Scale

Multifactorial Health Locus of Control Scale

Child Improvement Locus of Control Scale

NATIONAL INSTITUTE OF MENTAL HEALTH

FORM APPROVED
OMB NO. 68-R1288

Leave Blank – For Office Use Only

(1-5)

CARD 1 (6)

CHILDHOOD PERSONALITY SCALE (CPS)

(Factor Scale)

☐ FATHER
☐ MOTHER

FAMILY NAME	NAME OF CHILD DESCRIBED IN THIS FORM	(7)

INSTRUCTIONS: The purpose of this questionnaire is to get a picture of each child's personality as he or she typically has been for the last two months. Some of the sentences may describe this child very well. Other sentences will not be at all like this child. There are seven columns after each sentence. For each sentence, check the column that is most true of this child's personality and the way he acts.

THIS IS AN EXAMPLE OF THE TYPE OF QUESTION, AND HOW TO ANSWER IT:	NEVER	ALMOST NEVER	SELDOM	HALF THE TIME	FRE-QUENTLY	ALMOST ALWAYS	ALWAYS
	0	1	2	3	4	5	6
Happy to sing when there are guests in the house							

If this child always sings when there are guests, you should check column "6". If he never sings for company check column "0". If he sings sometimes but not always, check the box between "0" and "6" that best describes him.

	NEVER	ALMOST NEVER	SELDOM	HALF THE TIME	FRE-QUENTLY	ALMOST ALWAYS	ALWAYS	CARD 1 Col.
	0	1	2	3	4	5	6	
Loses interest in what he has started doing. Goes from one thing to another								(8)
Jumps, runs, and is on the move. Can't seem to be still for long								(9)
Turns his head away or looks down in an uncomfortable way when people pay attention to him								(10)
Lies down, rests his head, or falls asleep instead of playing								(11)
Babbles or talks with delight. Gets pleasure out of almost everything								(12)
Persists in trying to do something, even if he has some small problems along the way								(13)
Quickly shows his anger and frustration if he can't get something done that he's working on								(14)
Shies away from getting attention. Moves away from people								(15)
Sits without doing anything unless another person tries hard to get him interested								(16)
Will talk or babble to you about his toys, clothes, and what he is doing								(17)
Gives long attention to objects, toys, or books that interest him								(18)
Can get away from you "quick as a flash" when he wants to								(19)
Smiles to a friendly person								(20)
Seems to have little zest for normal activities. Acts tired								(21)
Talks and acts happily and with excitement about things that interest him								(22)

ADM 396-3
3-76

CONTINUE ON REVERSE SIDE

SENTENCE	0	1	2	3	4	5	6	Col.
Can pay attention for a long time to something								(23)
Active, impossible to keep up with him								(24)
Tends to be resistent and unfriendly								(25)
Would rather be left alone if you try to play with him or talk to him								(26)
Is a talkative child who expresses himself in language or near-language								(27)

Nowicki-Strickland Locus of Control Scale

YES	NO		
___	___	1.	Do you believe that most problems will solve themselves if you just don't fool with them?
___	___	2.	Do you believe that you can stop yourself from catching a cold?
___	___	3.	Are some people just born lucky?
___	___	4.	Most of the time did you feel that getting good grades meant a great deal to you?
___	___	5.	Are you often blamed for things that just aren't your fault?
___	___	6.	Do you believe that if somebody studies hard enough he or she can pass any subject?
___	___	7.	Do you feel that most of the time it doesn't pay to try hard because things never turn out right anyway?
___	___	8.	Do you feel that if things start out well in the morning that it's going to be a good day no matter what you do?
___	___	9.	Do you feel that most of the time parents listen to what their children have to say?
___	___	10.	Do you believe that wishing can make good things happen?
___	___	11.	When you get punished does it usually seem its for no good reason at all?
___	___	12.	Most of the time do you find it hard to change a friend's (mind) opinion?
___	___	13.	Do you think that cheering more than luck helps a team to win?
___	___	14.	Did you feel that it was nearly impossible to change your parents' mind about anything?
___	___	15.	Do you believe that parents should allow children to make most of their own decisions?
___	___	16.	Do you feel that when you do something wrong there's very little you can do to make it right?

YES	NO		
___	___	17.	Do you believe that most people are just born good at sports?
___	___	18.	Are most of the other people your age and sex stronger than you are?
___	___	19.	Do you feel that one of the best ways to handle most problems is just not to think about them?
___	___	20.	Do you feel that you have a lot of choice in deciding whom your friends are?
___	___	21.	If you find a four leaf clover do you believe that it might bring you good luck?
___	___	22.	Did you often feel that whether or not you did your homework had much to do with what kind of grades you got?
___	___	23.	Do you feel that when a person your age is angry at you, there's little you can do to stop him or her?
___	___	24.	Have you ever had a good luck charm?
___	___	25.	Do you believe that whether or not people like you depends on how you act?
___	___	26.	Did your parents usually help you if you asked them to?
___	___	27.	Have you felt that when people were angry with you it was usually for no reason at all?
___	___	28.	Most of the time, do you feel that you can change what might happen tomorrow by what you do today?
___	___	29.	Do you believe that when bad things are going to happen they just are going to happen no matter what you try to do to stop them?
___	___	30.	Do you think that people can get their own way if they just keep trying?
___	___	31.	Most of the time do you find it useless to try to get your own way at home?
___	___	32.	Do you feel that when good things happen they happen because of hard work?
___	___	33.	Do you feel that when somebody your age wants to be your enemy there's little you can do to change matters?

YES NO

___ ___ 34. Do you feel that it's easy to get friends to do what you want them to do?

___ ___ 35. Do you usually feel that you have little to say about what you get to eat at home?

___ ___ 36. Do you feel that when someone doesn't like you there's little you can do about it?

___ ___ 37. Did you usually feel that it is almost useless to try in school because most other children were just plain smarter than you?

___ ___ 38. Are you the kind of person who believes that planning ahead makes things turn out better?

___ ___ 39. Most of the time, do you feel that you have little to say about what your family decides to do?

___ ___ 40. Do you think it's better to be smart than to be lucky?

Multifactorial Health Locus of Control Scale

This is a questionnaire designed to determine the way in which different parents view certain important health-related issues. Each item is a belief statement with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. The more strongly you disagree with a statement, then the lower will be the number you circle. Please make sure that you answer every item and that you circle only one number per item. This is a measure of you personal beliefs; obviously, there are no right or wrong answers.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think we want you to believe.

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1. If I get sick, it is my own behavior which determines how soon I get well again.	1	2	3	4	5	6
2. No matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5	6
3. Having regular contact with my physician is the best way for me to avoid illness.	1	2	3	4	5	6
4. Most things that affect my health happen to me by accident.	1	2	3	4	5	6
5. Whenever I don't feel well, I should consult a medically trained professional.	1	2	3	4	5	6

		Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
6.	I am in control of my health.	1	2	3	4	5	6
7.	My family has a lot to do with my becoming sick or staying healthy.	1	2	3	4	5	6
8.	When I get sick I am to blame.	1	2	3	4	5	6
9.	Luck plays a big part in determining how soon I will recover from an illness.	1	2	3	4	5	6
10.	Health professionals control my health.	1	2	3	4	5	6
11.	My good health is largely a matter of good fortune.	1	2	3	4	5	6
12.	The main thing which affects my health is what I myself do.	1	2	3	4	5	6
13.	If I take care of myself, I can avoid illness.	1	2	3	4	5	6
14.	When I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.	1	2	3	4	5	6
15.	No matter what I do, I'm likely to get sick.	1	2	3	4	5	6
16.	If it's meant to be, I will stay healthy.	1	2	3	4	5	6
17.	If I take the right actions, I can stay healthy.	1	2	3	4	5	6
18.	Regarding my health, I can only do what my doctor tells me to do.	1	2	3	4	5	6

Child Improvement Locus of Control Scale

This is a questionnaire designed to determine the way in which different parents view certain important health-related issues. Each item is a belief statement with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. The more strongly you disagree with a statement, then the lower will be the number you circle. Please make sure that you answer every item and that you circle only one number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think we want you to believe.

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1. If my child decides to get better, he/she will.	1	2	3	4	5	6
2. My child's wellbeing is beyond anybody's control.	1	2	3	4	5	6
3. Professionals keep my child from getting worse.	1	2	3	4	5	6
4. My efforts at working with my child will probably result in his/her getting better.	1	2	3	4	5	6
5. If it is meant to be, my child will get better.	1	2	3	4	5	6

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
6. Where my child is concerned, the professional experts know what is best.	1	2	3	4	5	6
7. If my child decided to, he/she could be doing a lot better.	1	2	3	4	5	6
8. When I work harder at helping my child, he/she seems to do better.	1	2	3	4	5	6
9. God will decide what will happen to my child.	1	2	3	4	5	6
10. My child's progress depends mostly on what he/she does.	1	2	3	4	5	6
11. It takes professional knowledge and skill to help children like mine.	1	2	3	4	5	6
12. My child's wellbeing depends on me.	1	2	3	4	5	6
13. In order to get well, my child has to make up his/her own mind about getting well.	1	2	3	4	5	6
14. If my child gets proper professional care, he/she is more likely to get better.	1	2	3	4	5	6
15. Only God can help my child.	1	2	3	4	5	6
16. The things I do at home with my child are an important part of his/her recovery.	1	2	3	4	5	6
17. My child's progress depends on what the experts can do.	1	2	3	4	5	6

		Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
18.	My child's efforts to improve will eventually help him/her.	1	2	3	4	5	6
19.	My child's wellbeing is in God's hands.	1	2	3	4	5	6
20.	The things I do for my child can make all the difference in his/her improvement.	1	2	3	4	5	6
21.	My child is the master of his/her own destiny.	1	2	3	4	5	6
22.	Whether my child gets better or worse is just a matter of fate.	1	2	3	4	5	6
23.	My efforts are the most important thing in helping my child.	1	2	3	4	5	6
24.	Without professional help, my child probably would not get better.	1	2	3	4	5	6

APPENDIX D

PARENT EDUCATION GROUP

EVALUATION QUESTIONNAIRE

As you know, an important purpose of this series of meetings has been to gather information about what you as parents find helpful. Please answer the questions below as honestly and frankly as possible, so that we can use your feedback to improve the presentations that we offer parents in the future. These forms are anonymous.

PART I

1. Your Child's AGE RANGE:

_____ 0-5 yr. _____ attends pre-school/daycare center ____YES ____NO

_____ 6-12 yr. _____ grade in school _____

_____ 13-18 yr. _____ grade in school _____

_____ grade completed _____ employed ____Yes ____No

_____ Age when diagnosed with CF

_____ Number of Brothers/Sisters

_____ Number of other children with CF

2. What were the major areas of information about CF you and your child needed to understand most in the past year? (Check [✓] one or more of the following:)

_____ (a) Genetics (how inherited, CF gene carriers, family planning)

_____ (b) Physical therapy and postural drainage

_____ (c) Dietary management

_____ (d) Normal child development

_____ (e) School adjustment problems

_____ (f) Talking to your child about CF

_____ (g) Looking at your child's future life expectancy

_____ (h) Dating and marriage

_____ (i) Jobs and careers

_____ (j) CF research

COMMENTS: _____

_____

_____

3. How well would you judge you understood each of these areas a year ago? (Please Circle)

_____(a)	Genetics	a lot	some	little	none
_____(b)	Physical therapy & postural drainage	a lot	some	little	none
_____(c)	Dietary management	a lot	some	little	none
_____(d)	Normal child development	a lot	some	little	none
_____(e)	School adjustment problems	a lot	some	little	none
_____(f)	Talking to your child about CF	a lot	some	little	none
_____(g)	Looking at your child's future life expectancy	a lot	some	little	none
_____(h)	Dating and marriage	a lot	some	little	none
_____(i)	Jobs and careers	a lot	some	little	none
_____(j)	CR research	a lot	some	little	none

COMMENTS: _____

_____

_____

4. At this time how well do you think you understand each of these areas? (Please Circle)

_____(a)	Genetics	a lot	some	little	none
_____(b)	Physical therapy & postural drainage	a lot	some	little	none
_____(c)	Dietary management	a lot	some	little	none
_____(d)	Normal child development	a lot	some	little	none
_____(e)	School adjustment problems	a lot	some	little	none
_____(f)	Talking to your child about CF	a lot	some	little	none
_____(g)	Looking at your child's future life expectancy	a lot	some	little	none
_____(h)	Dating and Marriage	a lot	some	little	none
_____(i)	Jobs and careers	a lot	some	little	none
_____(j)	CF research	a lot	some	little	none

COMMENTS: _____

_____

5. Which of the following were most useful and comfortable to you? (Please check one)

_____(a) This series of parent groups

_____(b) Informal discussions with clinic staff

_____(c) Previous parent groups

6. Which of the following statements would best represent how you feel about the small groups you just completed? Please check one of these.

_____(a) They were interesting, but not very useful.

_____(b) They were useful as well as interesting.

_____(c) They were not very useful or interesting.

_____(d) Other _____

7. Of the following list of health professionals and others concerned with CF, please check those whom you felt were most useful to you in giving advise, information and support, both during these groups and in general.

_____(a) Clinic nurse

_____(b) Clinic physician

_____(c) Social workers

_____(d) Nutritionists

_____(e) Psychologists

_____(f) Physical therapists _____

_____(g) Play therapists

_____(h) Other parents

_____(i) CF foundation staff

_____(j) Local doctor

_____(k) Local nurse

_____(l) Others (Please specify) _____

8. If you think the CF Clinic ought to provide more counseling, what would you like to have the counseling focus on?

_____(a) Genetics

_____(b) Physical therapy

_____(c) Behavior

_____(d) Dating and marriage

_____(e) Jobs and careers

_____(f) Dietary management

_____(g) Medications

_____(h) Death and dying

_____(i) Needs of brothers and sisters

9. Given the opportunities available in the CF Clinic, which would you like to have more of?

_____(a) Group discussions

_____(b) Individual discussions with clinic personnel

_____(c) Other _____

PART II

FOR THE NEXT SET OF QUESTIONS, CIRCLE THE NUMBER THAT BEST REPRESENTS YOUR FEELINGS ABOUT EACH ITE
(LEAVE BLANK IF YOU MISSED THAT SESSION)

1. FIRST SESSION (MEDICAL INFORMATION)

	Not helpful			Helpful			Very Helpful
Material Presented	1	2	3	4	5	6	7
Method of Presentation	1	2	3	4	5	6	7
Group Interaction/Discussion	1	2	3	4	5	6	7

2. SECOND SESSION (GENETICS)

	Not Helpful			Helpful			Very Helpful
Material Presented	1	2	3	4	5	6	7
Method of Presentation	1	2	3	4	5	6	7
Group Interaction/Discussion	1	2	3	4	5	6	7

3. THIRD SESSION (NUTRITION)

	Not Helpful						Very Helpful
				Helpful			
Material Presented	1	2	3	4	5	6	7
Method of Presentation	1	2	3	4	5	6	7
Group Interaction/Discussion	1	2	3	4	5	6	7

4. FOURTH SESSION (PHYSICAL THERAPY)

	Not Helpful			Helpful			Very Helpful
Material Presented	1	2	3	4	5	6	7
Method of Presentation	1	2	3	4	5	6	7
Group Interaction/Discussion	1	2	3	4	5	6	7

5. FIRST SESSION, COMMUNICATION SKILLS (PROBLEM OWNERSHIP)

	Not Helpful						Very Helpful
Material Presented	1	2	3	4	5	6	7
Method of Presentation	1	2	3	4	5	6	7
Group Interaction/Discussion	1	2	3	4	5	6	7

6. SECOND SESSION, COMMUNICATION SKILLS (ACTIVE LISTENING)

	Not Helpful			Helpful			Very Helpful
Material Presented	1	2	3	4	5	6	7
Method of Presentation	1	2	3	4	5	6	7
Group Interaction/Discussion	1	2	3	4	5	6	7

7. THIRD SESSION, COMMUNICATION SKILLS (I-MESSAGES)

	Not Helpful			Helpful			Very Helpful
Material Presented	1	2	3	4	5	6	7
Method of Presentation	1	2	3	4	5	6	7
Group Interaction/Discussion	1	2	3	4	5	6	7

8. FOURTH SESSION, COMMUNICATION SKILLS (MUTUAL PROBLEM SOLVING)

	Not Helpful			Helpful			Very Helpful
Material Presented	1	2	3	4	5	6	7
Method of Presentation	1	2	3	4	5	6	7
Group Interaction/Discussion	1	2	3	4	5	6	7

PART III

1. OVERALL, HOW WOULD YOU RATE THE TOTAL GROUP EXPERIENCE?

Not Helpful			Helpful			Very Helpful
1	2	3	4	5	6	7

OVERALL, WHICH ASPECT OF THE GROUP MEETING PROGRAM WAS:

2. Most helpful?

3. Least helpful?

4. Most interesting?

5. Least interesting?

6. IF YOU THINK THE GROUPS COULD BE IMPROVED UPON, CHECK THE ITEMS SHOWING HOW YOU WOULD CHANGE THE GROUPS; YOU MAY CHECK MORE THAN ONE.

_____(a) Larger groups

_____(b) Smaller groups

_____(c) More technical information

_____(d) Less technical information

_____(e) More focus on specific problems

_____(f) Less focus on specific problems

_____(g) More parent participation and leadership

_____(g) Less parent participation and leadership

APPENDIX E

Basic Knowledge of Cystic Fibrosis

True or False: Decide whether each statement is true or false. Check T or F.

1. There is a 1 in 4 chance of having a CF child in each pregnancy when both parents carry the CF gene.

   T _____ F _____

2. At the present time, there is no test for finding out who does or does not carry a CF gene.

   T _____ F _____

3. There is no known cure for CF at present.

   T _____ F _____

4. Of all body organs the lungs are most severely affected by CF.

   T _____ F _____

5. One way to help loosen and remove mucus from the lung is to do chest physical therapy and drainage.

   T _____ F _____

6. It is possible to get rid of all the thick mucus in the lungs.

   T _____ F _____

7. Eventually, each child with cystic fibrosis will develop lung symptoms such as coughing and infections.

   T _____ F _____

8. Mucus in the airway cuts down on the amount of air that can move in and out of the lungs.

   T _____ F _____

9. It is always possible to clear up lung infections by giving antibiotic medicine by mouth.

   T _____ F _____

10. All children with CF have exactly the same health problems and are treated alike.

T _____ F _____

11. Most males with CF are sterile.

T _____ F _____

12. Young adult females with CF are usually sterile.

T _____ F _____

Multiple Choice: There may be more than one correct answer for each question. Check all answers that you think are correct.

13. CF may occur in a child if:

_____ 1 parent carries 2 CF genes.
_____ each parent carries a CF gene.
_____ there is something missing in the mother's diet during pregnancy.

14. The major problems in CF seem to be caused by the:

_____ salty sweat _____ thick mucus

15. Children with CF are helped to gain weight by:

_____ taking antibiotics _____ coughing up the mucus
_____ taking enzymes _____ increasing the amount of calories in their diet

16. The digestive organ most often affected by the thick mucus is the:

_____ stomach _____ pancreas _____ liver

17. What does this organ produce that is needed to break down foods in the small intestine?

_____ enzymes _____ calories _____ salt

18. If a child with CF is not taking the right amount of enzymes or foods, you may notice:

_____ increased number of stools/day.
_____ poor weight gain.
_____ very large appetite.

19. Thick mucus in the lungs may cause:

_____ clogged airways.
_____ infections.
_____ a chronic cough.

20. In order to help loosen and remove the mucus from the lungs, your child is encouraged to:

_____ be physically active.
_____ play only quiet games.
_____ take enzymes.
_____ take vitamins.

APPENDIX F

Children's CF Knowledge Questionnaire

Look at all of these things, they are pictures of parts of our bodies.

_____1. Pick out for me which one is the HEART.

_____2. Pick out for me which one is the BRAIN.

_____3. Which one is the STOMACH?

_____4. Which one is the LUNGS?

_____5. Which one is the PANCREAS?

_____6. Which one is the INTESTINES? (GUTS?)

_____7. This one is supposed to be the HEART. I want you to look at this picture of a person, and put his heart in where you think it ought to go.

_____8. Put his BRAIN in where it belongs.

_____9. Put his STOMACH in where it belongs.

_____10. Put his LUNGS in where they belong.

_____11. Put his PANCREAS where it belongs.

_____12. Put his INTESTINES (Guts) where they should go.

_____13. Which one of these things helps you think? _____

_____14. Which one of these things pumps your blood? _____

_____15. Which one of these things helps break down your food so your body can use it? _____

_____16. You can pick more than one! _____

_____17. _____

_____18. Which one helps you breath? _____

_____19. Which parts of the body are most bothered by cystic fibrosis? _____

_____20. _____

_____21. _____

_____22. When you have your physical therapy, which part of your body does it help most?

_____

_____23. When you take your viocase or pancrease, where does it do its work?

_____

_____24. How do you help loosen and get the mucus our of your lungs?

_____

_____25. Will the cystic fibrosis go away? _____

_____26. How did you get Cystic Fibrosis? _____

_____

_____27. It is good for you to run and play? _____

_____28. Why or why not? _____

_____29. Why do you need to take your enzymes with your meals? _____

_____

_____30. How does your body tell you if you haven't taken enough enzymes?

_____

MANUAL FOR CHILDREN'S CF KNOWLEDGE QUESTIONNAIRE

Questions 1-23

For questions 1-6, spread the body parts out on the table, keeping the figure hidden. Casually draw the child's attention to each one as you say "look at all these things." Make sure the child points or picks up one item in response to each question. Replace each one after the choice. Do not let the child know whether he is correct or incorrect; use neutral comments such as "good job" or "thank you". At the end of the 6, say "you did a really good job". Record in the space on the left with either a 1 if correct or a blank; if wrong, fill in 0's for the blank's later, so as not to give observant children clues.

For questions 6-12, take out the figure, and gather up the body parts. Hand them to the child one at a time, in the order indicated. If the child had chosen correctly, say, "rember that this was the _____" or simply, "put the _____ where it goes." If the original choice was incorrect, say something like "Actually, this was supposed to be _____." "Put this _____ where it belongs." After each placement, record 1 or leave blank. Remove the body part after you score each placement.

SEE ATTACHED SKETCH FOR SCORING.

Questions 13-23: Put away figure, leave body parts spread out on table. Score either verbal responses or selection of correct body part. Record answer verbatim. Note: #15-17, give one point for stomach, one point for pancreas, and one point for intestines. Score 1 or blank as above. For

example, if the child says "stomach" only, he gets 1 out of a possible 3 points. If he says "stomach, pancreas, intestines" he gets 3 points, shown by marking 15, 16, 17 correct.

#19-21: Give one point for lungs, one point for pancreas, and one point for intestines, as above.

#22: Correct answer is LUNGS.

#23: Score correct if child says INTESTINES, GUTS or STOMACH. The answer "PANCREAS" gets no credit. If needed, may clarify that you mean "enzymes" or "Pills you take at meals."

#24-30: Record answer verbatim in space provided: score 1 or 0 later.

#24: Any answer referring to exercise, running around, physical therapy, postural drainage, clapping or beating.

#25: The only correct answer is "no". Child may qualify by saying "unless the doctors find a new cure" or "unless Godd makes a miracle" but must clearly indicate that they know that in the normal course of events, their disease will not go away.

#26: Child must get idea of being born with disease. This would include such answers as "always had it," "born this way," "from my parents."

#27: Correct answer is YES. Child may qualify with "unless I'm sick."

#28: Must explain about the benefits of exercise in helping secretions move out of lungs, helping breathe better, etc.

#29: Correct answer could be any of the following: answers referring to helping the body use food, helping child gain weight, helping with digestion. If child says "so won't get sick: or other vague answer,

probe: "Tell me more.... in what way would you be sick?"

#30: Any reference to abdominal or stomach pain or discomfort, or abnormalities in bowel movements.

SCORING PLACEMENT OF BODY PARTS

BRAIN - entirely in head

HEART - above navel, below neckline, some part of nipples must show

STOMACH - below nipples, above hip dimple

LUNGS - above navel, below chin, covering nipples

PANCREAS - below nipples, above hip dimple

INTESTINES or GUTS - below nipples, covering navel

APPENDIX G

Children's Nowicki-Strickland Locus of Control Scale

YES	NO		
___	___	1.	Do you believe that most problems will solve themselves if your just don't fool with them?
___	___	2.	Do you believe that you can stop yourself from catching a cold?
___	___	3.	Are some kids just born lucky?
___	___	4.	Most of the time do you feel that getting good grades means a great deal to you?
___	___	5.	Are you often blamed for things that just aren't your fault?
___	___	6.	Do you believe that if somebody studies hard enough he or she can pass any subject?
___	___	7.	Do you feel that most of the time it doesn't pay to try hard because things never turn out right anyway?
___	___	8.	Do you feel that if things start out well in the morning that it's going to be a good day no matter what you do?
___	___	9.	Do you feel that most of the time parents listen to what their children have to say?
___	___	10.	Do you believe that wishing can make good things happen?
___	___	11.	When you get punished does it usually seem it's for no good reason at all?
___	___	12.	Most of the time do you find it hard to change a friend's (mind) opinion?
___	___	13.	Do you think that cheering more than luck helps a team to win?
___	___	14.	Do you feel that it's nearly impossible to change your parent's mind about anything?
___	___	15.	Do you believe that your parents should allow you to make most of your own decisions?

YES NO

___ ___ 16. Do you feel that when you do something wrong there's very little you can do to make it right?

___ ___ 17. Do you believe that most kids are just born good at sports?

___ ___ 18. Are most of the other kids your age stronger than you are?

___ ___ 19. Do you feel that one of the best ways to handle most problems is just not to think about them?

___ ___ 20. Do you feel that you have a lot of choice in deciding who your friends are?

___ ___ 21. If you find a four leaf clover do you believe that it might bring you good luck?

___ ___ 22. Do you often feel that whether you do your homework has much to do with what kind of grades you get?

___ ___ 23. Do you feel that when a kid your age decides to hit you, there's little you can do to stop him or her?

___ ___ 24. Have you ever had a good luck charm?

___ ___ 25. Do you believe that whether or not people like you depends on how you act?

___ ___ 26. Will your parents usually help you if you ask them to?

___ ___ 27. Have you felt that when people were mean to you it was usually for no reason at all?

___ ___ 28. Most of the time, do you feel that you can change what might happen tomorrow by what you do today?

___ ___ 29. Do you believe that when bad things are going to happen they just are going to happen no matter what you try to do to stop them?

___ ___ 30. Do you think that kids can get their own way if they just keep trying?

___ ___ 31. Most of the time do you find it useless to try to get your own way at home?

___ ___ 32. Do you feel that when good things happen they happen because of hard work?

YES	NO		
___	___	33.	Do you feel that when somebody your age wants to be your enemy there's little you can do to change matters?
___	___	34.	Do you feel that it's easy to get friends to do what you want them to?
___	___	35.	Do you usually feel that you have little to say about what you get to eat at home?
___	___	36.	Do you feel that when someone doesn't like you there's little you can do about it?
___	___	37.	Do you usually feel that it's almost useless to try in school because most other children are just plain smarter than you are?
___	___	38.	Are you the kind of person who believes that planning ahead makes things turn out better?
___	___	39.	Most of the time, do you feel that you have little to say about what your family decides to do?
___	___	40.	Do you think it's better to be smart than to be lucky?

NOTE:

The Moos Family Environment Scale, Self-Observation Scales, the Pre-School and Primary Nowicki-Strickland Locus of Control Scale, and the Children's Health Locus of Control Scale could not be reproduced due to copyright restrictions. However, they are readily available through the sources listed in the References.